CONNECTING WITH MENTAL HEALTH CARERS IN THE GREAT SOUTH COAST

**A report produced as part of the
2017 LEADERSHIP GREAT SOUTH COAST PROGRAM**

PROJECT LEADERS
• Leon Carey
• Alison Kennedy
• Vicki Askew Thornton

ACKNOWLEDGEMENTS

We would like to acknowledge the following people, without whose help this project would not have been possible:

PROJECT REFERENCE GROUP

• **Bess Slater** - Manager, Fund-raising and Sustainability, Lifeline South West Victoria; Fight For Your Life
• **Tracey Morriss** - Child Youth and Family Support, Wellways Australia Limited
• **Betty Kenna** - Carer, The Sisters
• **Alison Tickner** - Carer Consultant, Mental Health Services, South West Healthcare

PROJECT MENTORS

• **John Parkinson** - Community Relations/Mental Health Manager, St John of God Hospital Warrnambool
• **Michael Hoffman** - Community Awareness & Engagement Coordinator, Community and Youth Complex, Headspace Warrnambool
• **Amanda Hennessy** - Executive Officer, Leadership Great South Coast
• **Fiona Younis** - Regional Manager, Wellways Australia Limited

OTHERS

• **Wattle Tree Carers Group members**
• **The 52 survey respondents**

INTRODUCTION

KNOWLEDGE FROM PREVIOUS RESEARCH

A range of previous research has been conducted on the challenges and experience of carers in Australia. This research includes efforts to understand who is conducting the caring role [1], the nature of their caring role [1] and the barriers and enablers [2] they face as part of the caring experience. The influence of the rural context has been considered in the context of caring for older people [2-5]. This rurally focused research identified a strong reliance on informal care networks—such as friends and family—with less reliance on formal services [5]. Lack of available respite or crisis care was also identified as an issue for carers [5].

While research has been conducted about carers of someone with a mental health condition, this has generally had an urban focus [1, 6]. These studies identified challenges to carer's own mental health [7] as well as financial burdens, limited support and training, and an increasing shift of responsibility for care from health professional to carers [6]. A further concern has been the lack of consultation with carers about the treatment of the person they are caring for [8].

Although the broader body of research to date is valuable for informing the directions of support for carers, no previous efforts have considered the needs of carers of someone living with a mental health condition within the specific regional and rural context of the Great South Coast.

BACKGROUND TO THE PROJECT

Leadership Great South Coast (LGSC) Community Projects

As part of the LGSC Program, participants are required to form project teams to complete community projects. Project ideas can be put forward by participants, LGSC Alumni, LGSC Committee members, LGSC staff, local government and community representatives. Each project must have direct benefit to the Great South Coast region and align with one or more of the Great South Coast Strategic Plan priorities. All projects engage local leaders as mentors who provide connections, support and advice to the project teams. On completion, each project team makes a presentation to the LGSC Committee. The presentation summarises the project process and outcomes. It must also provide a reflection on the leadership and project management skills developed by the team members. More information about the LGSC program and the community projects is available via the following links:

http://www.leadershipgreatsouthcoast.org.au/

http://www.leadershipgreatsouthcoast.org.au/projects/

Local Knowledge

Informal discussions with mental health carers in the Great South Coast Region identified significant life changes based on having become a carer (involuntarily) and the challenges this poses. Anecdotal evidence suggests these carers often have no voice, no formal experience in caring, insufficient support and little recognition for the work they do. Being a carer restricts people's social networks, employment opportunities, personal time and space. However, carers had also informed the team that life as a carer also had positive aspects. This project and resulting report was a means of conveying this voice—in a more formal, evidence-based and actionable manner—to groups within the Great South Coast who have capacity and resources to act upon the information and recommendations made.

SIGNIFICANCE OF THE PROJECT

Connecting with Carers is significant on a number of levels:

- Giving personal voice to mental health carers.
- Providing a clearer understanding of the met and unmet needs of mental health carers.
- Providing evidence-based recommendations to an organisation that has the capacity to act.
- Facilitating improved services and appropriate resources for mental health carers in the Great South Coast region.
- Providing a framework for developing similar needs assessments for other carers in the region (for example: carers of the aged, carers of those living with intellectual or physical disability, carers of those with a terminal illness).

PROJECT SCOPE

It was necessary to define the scope of the project within the time and resource limitations of a community project. In the project development phase, the following inclusions and exclusions were defined:

This project will include:

- Drafting the resource based on the qualitative and quantitative data gathered, including recommendations for meeting unmet needs, and presenting to the PRG for review (as required).
- Finalising the resource including recommendations.
- Presenting the resource to the stakeholder organisations, including Fight For Your Life and other interested parties.

This project will not include:

- The implementation of recommendations.
- Ongoing support or advice from the project team following presentation and handover of the resource.

PROJECT DESIGN

AIMS OF THE PROJECT

- To identify and document the stories and needs of mental health carers from the Great South Coast (GSC) region.
- Compile the findings into a comprehensive resource including recommendations for delivering unmet needs. Present the report to stakeholder organisations including Fight For Your Life and Wellways Australia.

THE PROJECT TEAM

LEON CAREY (PROJECT LEAD)

Southern Cross Kitchens business owner and
Hands on Learning Artisan Teacher Leader at
Warrnambool College

VICKI ASKEW-THORNTON

Major Projects Liaison and Economic Development Officer,
Moyne Shire Council

ALISON KENNEDY

Research Fellow,
Deakin University/National Centre for Farmer Health

The Project Reference Group

A Project Reference Group (PRG) was established in June 2017, comprising representatives of stakeholder organisations and carers. Recruitment to the PRG was achieved by project team members communicating with known contacts from the mental health sector across the region. Informal discussions were held in-person, via phone and email to establish willingness and ability to be involved. From this, a small group of skilled and experienced people were recruited.

Two formal PRG meetings were held during the project, in July and September 2017. Between meetings the project team communicated with the PRG via individual meetings, emails and telephone.

The role of the PRG was to:

• Assist with recruiting carers to the survey.

• Provide feedback on the program plan.

• Provide feedback on project documents including the draft survey and the draft project report.

• General advice and information about the GSC mental health sector and carer networks as required.

Project Mentors

A group of project mentors were sourced from across the mental health sector to provide valuable advice and support to the project team on an informal basis, particularly in the planning and recruitment stage.

DEVELOPING THE PROJECT TOOLS

An initial online survey was chosen as the preferred method of data collection in order to be able to gather a significant amount of data in the short time frame available for the project. The project team developed draft survey questions to reflect the project's aims. Once the survey was drafted it was distributed to the PRG for consideration prior to the first PRG meeting. At that meeting, minor improvements were discussed, changes made and the final survey was produced (see Appendix 1).

The team believed it was important to make the survey as accessible as possible for carers. It was recognised that not all potential participants would have quality access to online technologies. Given this, the survey was also available in a hard copy format. Although most of the surveys were completed online, a small number of surveys were completed and submitted in hard-copy format.

Follow-up qualitative interviews were also considered—in the project planning stage—as a way of gathering further data from willing survey participants. The final question in the survey asked if the person would be willing to share more detail about their caring experience, and provided a space for them to include their contact details. It was noted in this section of the survey that any personal information shared would remain anonymous, and contact details would not be used for any other purpose than to contact them for this research. However, the richness of data collected via the surveys (including quantitative and qualitative data) was considered to be adequate for the scope of the project.

RECRUITMENT TO THE SURVEY

Conversations with Key Individuals

Between July and September, project team members held many face-to-face, phone and email conversations with key people from the GSC mental health sector to promote the project and recruit carers to the survey. This process was evolutionary, with many of these conversations resulting in referral to other sources of dissemination.

Use of 'KUMU' Software

Lifeline provided the project team with access to a spreadsheet of 36 service providers in the GSC region that offer support services to carers of people with a mental health condition. The list was generated by 'Kumu', an advanced interactive stakeholder mapping resource. The list contained several additional services that had not been identified through other means. The relevant service providers were then emailed an introductory description of the project, a flyer and a request to forward the survey link to carers registered with their organisations.

Recruitment Flyer

Early in the project, a one-page flyer was designed to promote the project aims and advertise the survey (see Appendix 2). The flyer was emailed across the GSC region to relevant service providers, key organisations and individuals that could assist in recruiting carers to the survey.

Press Release

O2 Media was engaged to develop a press release about the project which was published in the Warrnambool Standard newspaper and on its website on 11 September (see Appendix 3). The article included the survey link and contact details for more information.

Wattletree Rural Carers

Having developed a relationship with Wellways Australia (Warrnambool), the team was invited to meet with the Wattletree Rural Carers group. This self-help group meets on a monthly basis, providing information, advocacy, peer support and friendship. The group comprises carers from across the GSC region, of different ages and backgrounds.

Members of the project team attended two Wattletree Rural Carers meetings, on 4th August and 1st September, 2017. At the first meeting the project was explained to the Wattletree group and the survey was promoted. At the second meeting, the project team updated the carers group on the project's progress and collected some completed hard copy surveys. Further surveys were completed and submitted at that meeting. Through open discussion, the carers also provided the team with verbal insights into their lives as carers, providing context and supporting the rationale for the project.

RESULTS

A total of 52 surveys were received in the period of recruitment (N=52). 47 of these were received online and 5 were completed on a hard copy survey and entered manually online by one of the research team. Not all participants answered every question. Respondent numbers for each individual question are identified in the figure headings below.

DEMOGRAPHICS

Participants spanned a range of age groups with 17.7% aged 25-34 years, 23.5% aged 35-44, the largest group of 29.4% aged 45-54 years, 21.6% aged 55-64 years and 7.8% of carers over the age of 65 years (see Figure 1). The only group that was not represented in the survey were those aged 18-24 years.

Figure 1: Participant Age Range (N=51)
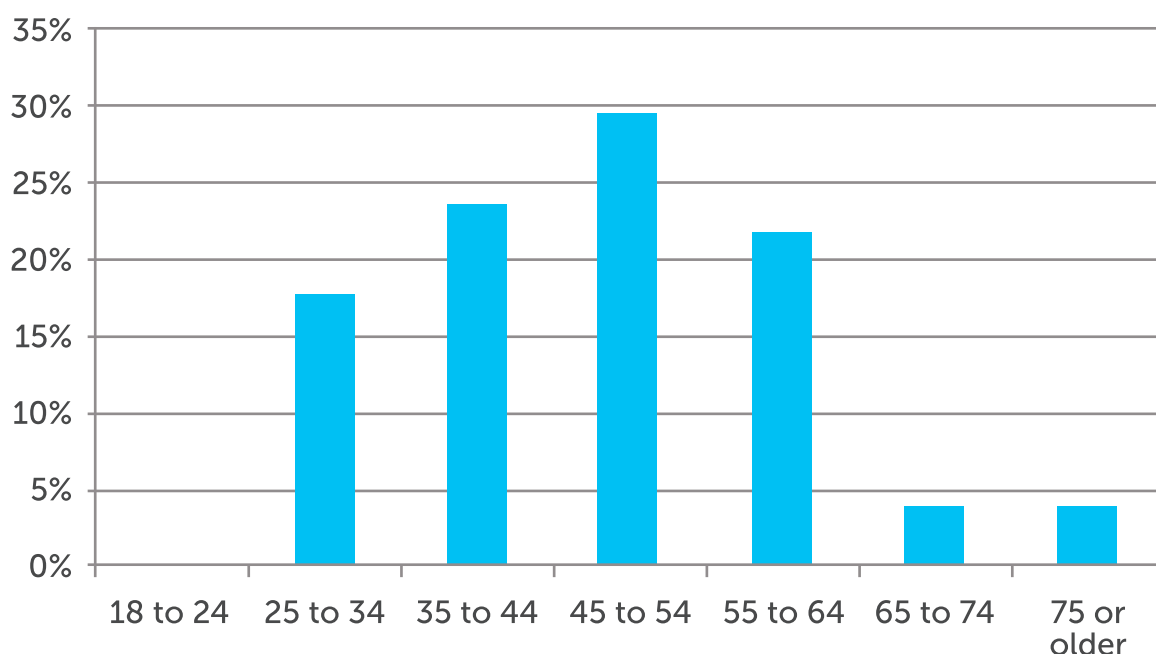
All Great South Coast Local Government Areas (LGAs) were represented in the survey (see Figure 2). The largest group of carers came from Warrnambool City (35.3%), followed by Southern Grampians (27.5%), Moyne (21.6%), Glenelg (9.8%) and Corangamite (5.9%) Shire Councils. The higher rate of return from the Warrnambool City Council area reflects its population (34% of the GSC population at 34,000) compared to the four other Local Government Areas in the GSC of Moyne (16,000), Southern Grampians (16,000), Corangamite (16,000) and Glenelg (19,000). Southern Grampians and Moyne Shires are over-represented in the survey, relative to their population. This is likely to be a reflection of the fact that members of the project team came from these areas and engaged local contacts in promoting the invitation to participate in the project.

Figure 2: Residential LGA of Participants (N=51)

- **6%** Corangamite
- **10%** Glenelg
- **22%** Moyne
- **27%** Southern Grampians
- **35%** Warrnambool
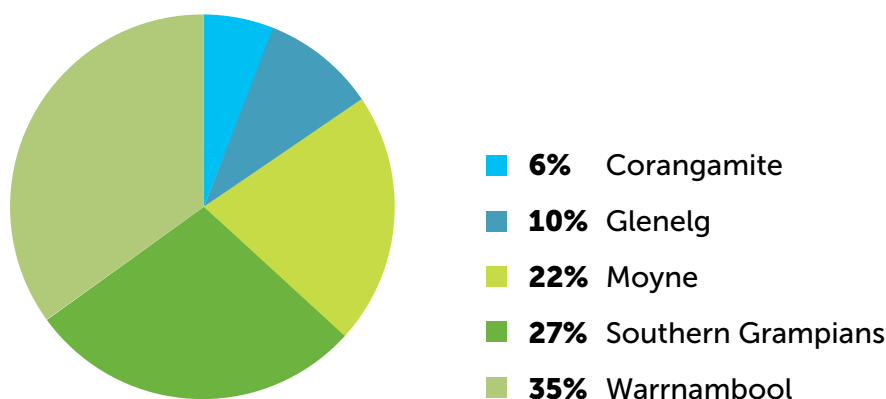
All responding participants (N=47) identified their main language spoken at home as English.

Only two participants (from N=50 reporting) identified as being of Aboriginal or Torres Strait Islander Status.

The majority of participants described being in either full-time (41.2%) or part-time/casual (39.2%) paid employment in addition to their caring role (see Figure 3). Only one person described involvement in either full-time or part-time study and nobody was actively seeking work. Only one person was receiving a carer's pension. Only two people (6%) identified as being involved in volunteer work. This is much lower than the general population volunteerism rate for the Warrnambool region of 29.9% as reported in the ABS 2011 Census [9]. This is likely to reflect the demands on time required when caring for someone with a mental health condition.

Figure 3: What is your current employment/study status (you can choose more than one answer)? (N=51)

- Full time employment
- Part-time or casual employment
- Not employed but seeking work
- Retired
- Working as a volunteer
- Full time study
- Part time study
- Unpaid carer
- Carer pension
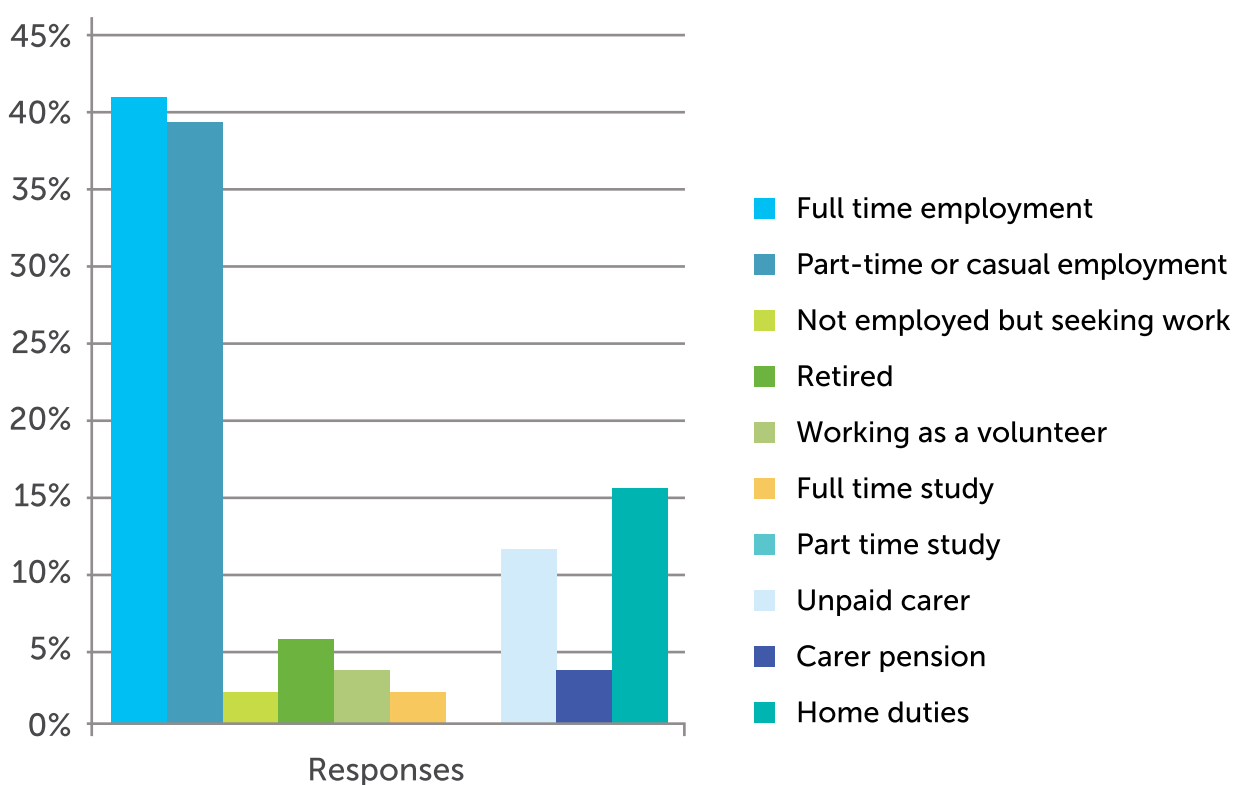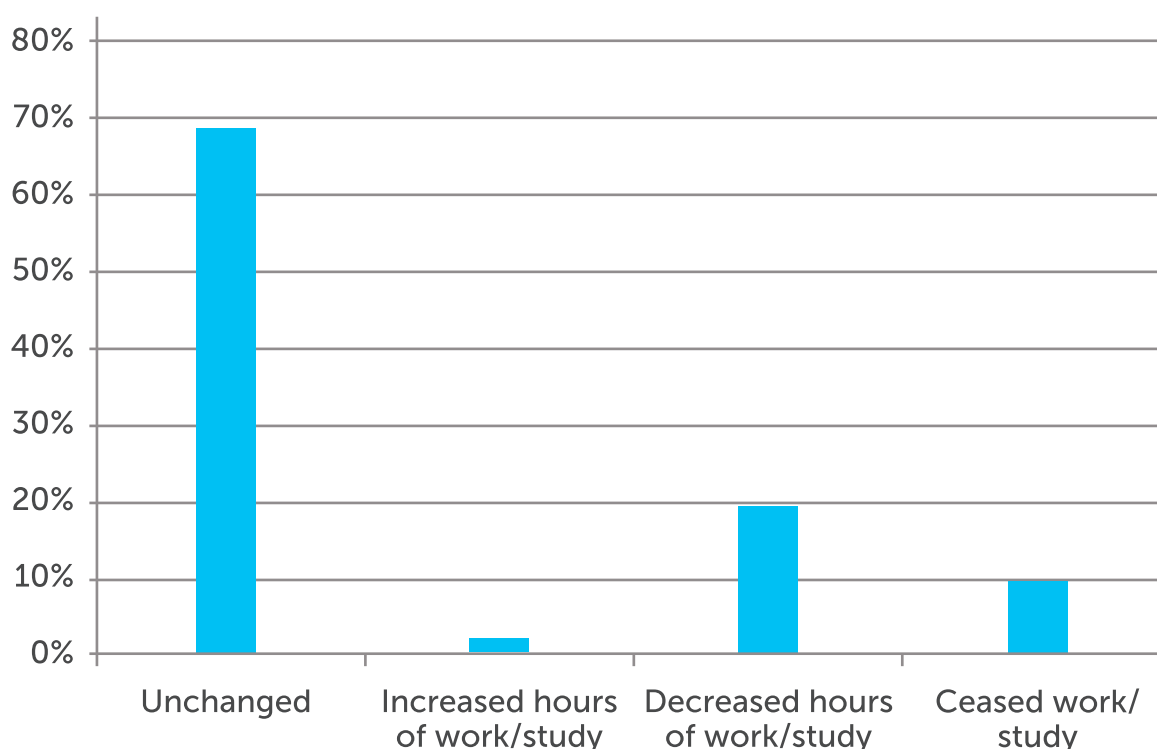- Home duties

Responses

Figure 4: Change in employment/study as a result of becoming a carer (N=50)

The majority of participants described their employment or study status as being unchanged as a result of their caring responsibilities (68.0%)(see Figure 4). However, a significant minority reported having either reduced their hours of work/study (20.0%) or ceasing work/study entirely (10.0%) as a result of their caring role.

CARING STATUS

Three quarters of participants reported caring for one person living with a mental health condition, with the remaining participants caring for two or more people (see Figure 5). The proportion of respondents caring for three or more people was 8% (representing 4 responding carers).

Figure 5: Number of people living with a mental health condition partcipants care for (N=49)

- **76%** One
- **14 %** Two
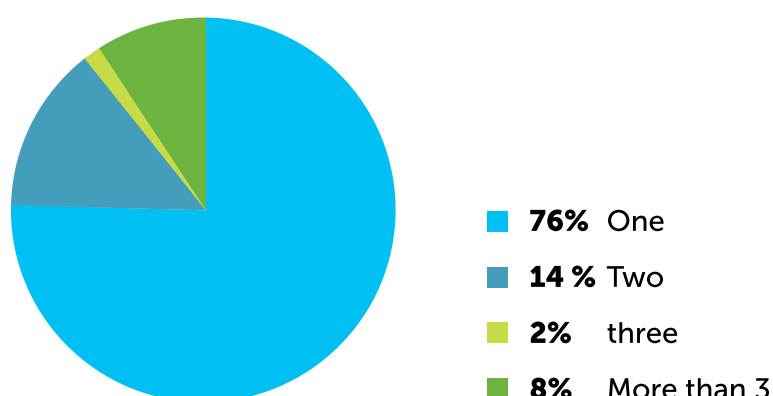- **2%** three
- **8%** More than 3

Figure 6 identifies the combined length of caring that each participant had been involved in, regardless of the number of people they had cared for within this period. There was representation of both recent and long-term carers in the survey results. Twenty eight per cent had been in a caring role for between one and three years. The majority of participants had held a caring role for greater than 3 years (64%), with 18% of carers having been in a caring role for over 20 years. This resulted in participants finding that the caring role became a dominant focus of their current lives and their future. As described by one participant:

> *"[Caring is…] a tough gig but [I] do not want to hand over total care of my children just yet. [I] have a 5 year plan. [I] do want to have them settled into SAH (supported accommodation housing) so that we can all be used to this before we are forced to move to this step. We have just about ceased thinking about ourselves as we have been doing this for so long and really do not know any different and it is our norm." (#20)*

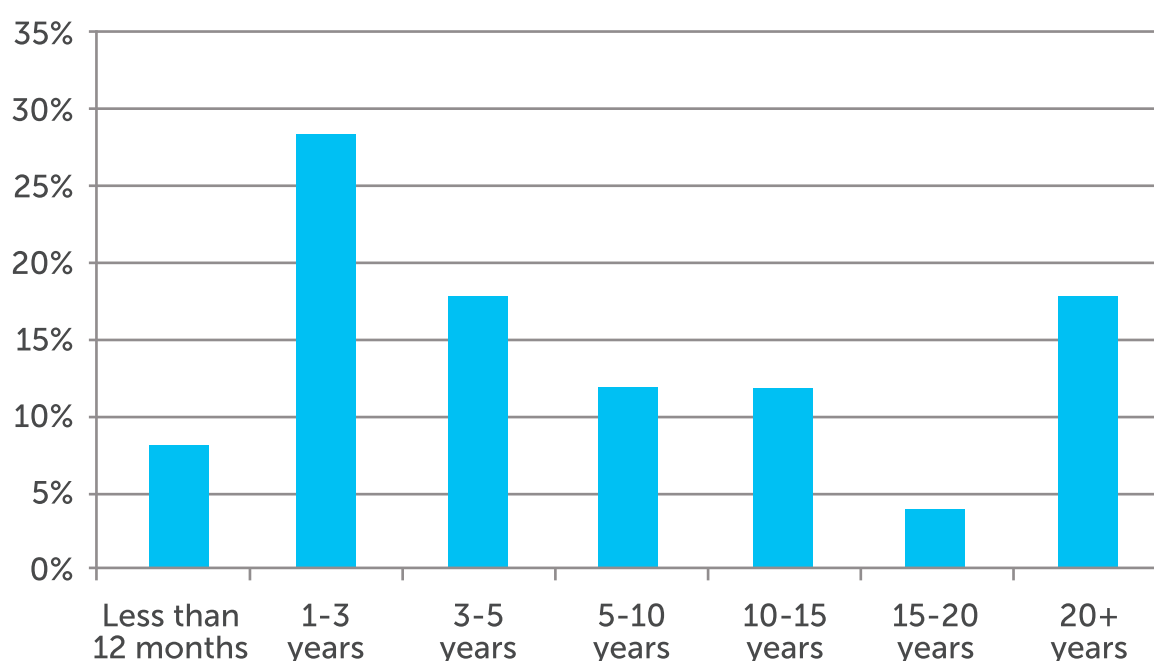## Figure 6: Combined length of caring role for each participant (N=50)

Figure 7 represents the age of the person(s) with a mental health condition being cared for by participants. A broad spread of ages of persons cared for was represented within the survey. The largest age group under the care of participants was those aged 18 to 24 years. This is not surprising considering that young Australian adults (aged 16-24 years) have the highest rates (26%) of reported mental health conditions within a 12 month period of any age group [10], combined with the fact that young people of this age may still be living at home—and therefore, receiving some care from parents—independently of their mental health status. In addition to this, research has shown that approximately 75% of mental health conditions develop prior to the age of 25 years [11].

Figure 7: Age of person(s) being cared for (N=50)
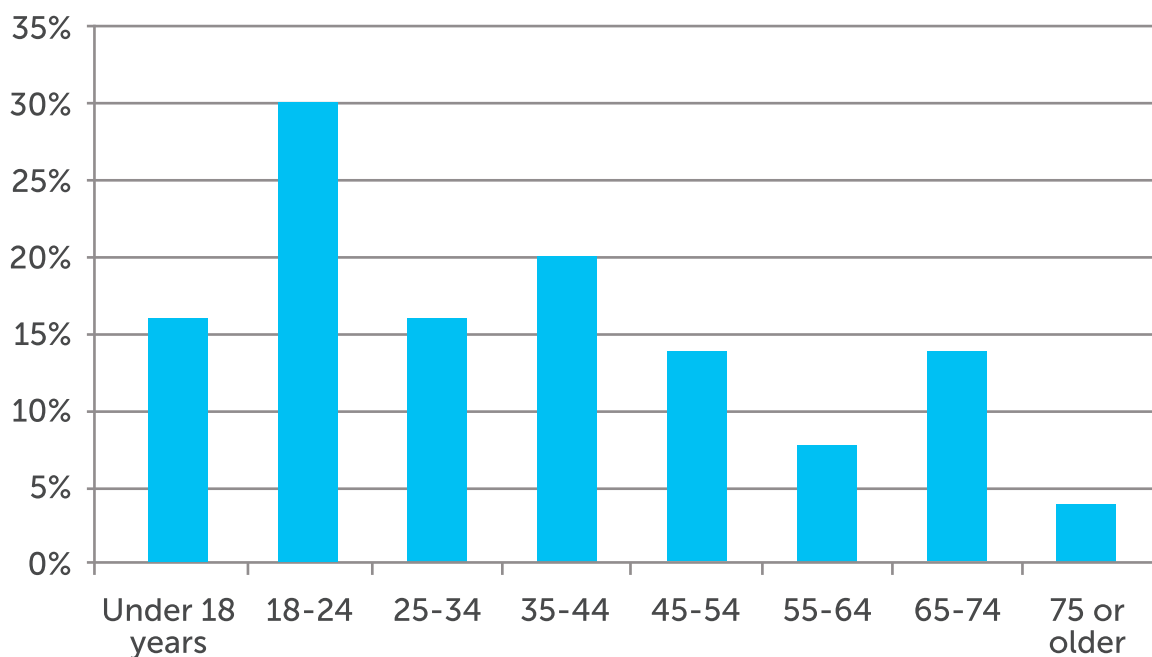
Reflecting the age of people being cared for in Figure 7, Figure 8 identifies that 40% of relationships are children being cared for by parents. Qualitative data from participants (discussed later in this report) suggests that parents with a caring role—when combined with caring for other family and children—face additional challenges.

A further quarter of participants were caring for a spouse, while 12% were caring for a parent. Of those who marked 'other', participants were caring for siblings, extended family and—in two cases—a work colleague or friend. Additional data collected also indicated that the majority (66%) of carers live with the person they are caring with. Shared residency is likely to contribute to many carer's experience of finding their role all-consuming and finding it difficult to take time out from their caring role.

Figure 8: Carers' relationship with the person they have cared for the longest. They are the carers' ..... (N=50)

- **40%** Child
- **26%** Spouse/partner
- **14%** Other
- **12%** Parent
- **8%** Friend
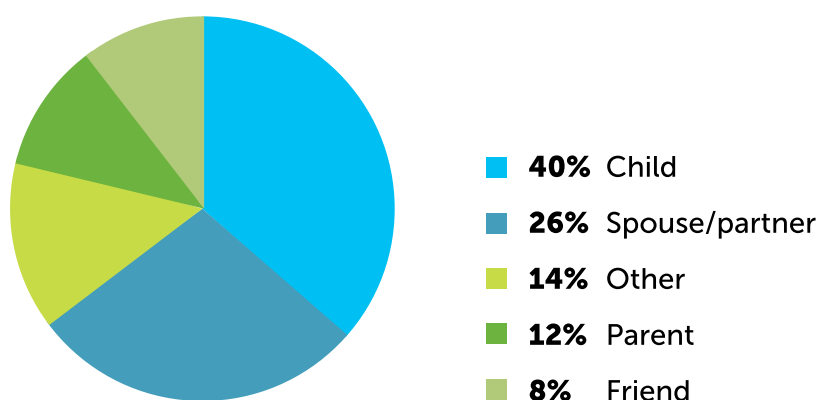
While a range of mental health conditions were experienced by those being cared for (see Figure 9), the greatest prevalence (56%) was of depression and/or anxiety. This is not surprising given that depression and anxiety are some of the more commonly experienced mental health conditions across Australia [12]. This was followed by dual or multiple diagnoses (18%) and bipolar disorder (14%) and other disorders (6%) including Alzheimer's, acquired brain injury and Obsessive Compulsive Disorder. The significant number of participants with experience of caring for someone with multiple disorders is also not surprising. Statistics suggest that of the 20% of Australians experiencing a diagnosed mental health condition in any single year, over half will experience one disorder and the remaining will experience two or more disorders [12]. Only two participants were caring for someone living with schizophrenia (4%) and one was caring for someone with alcohol and drug addiction (2%).

Figure 9: What condition is the person you are caring for living with? (N=50)
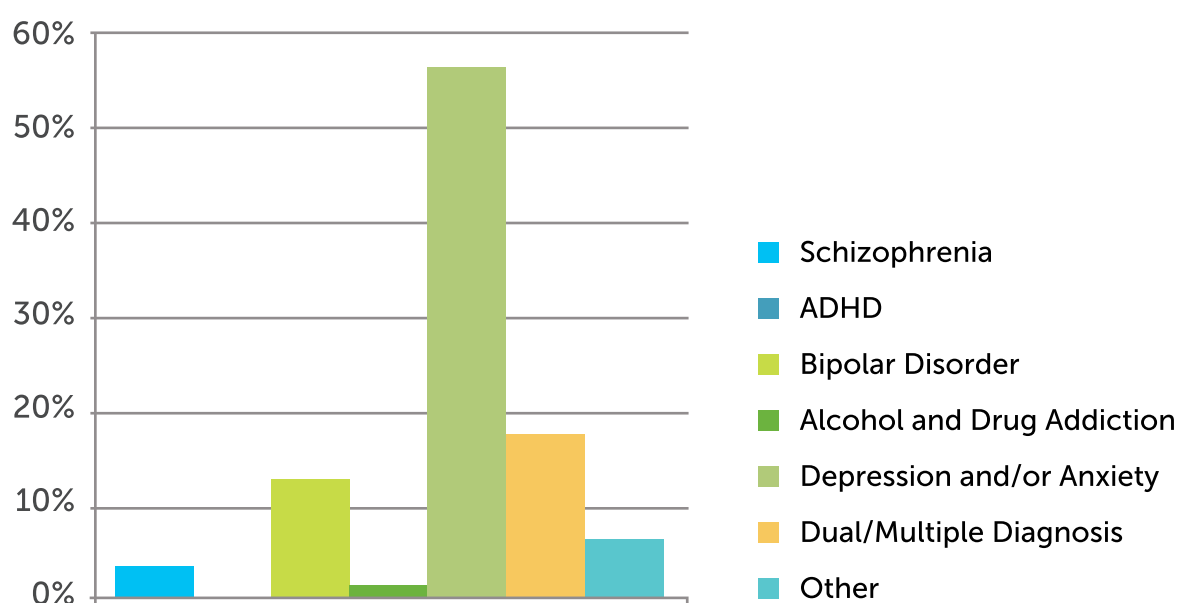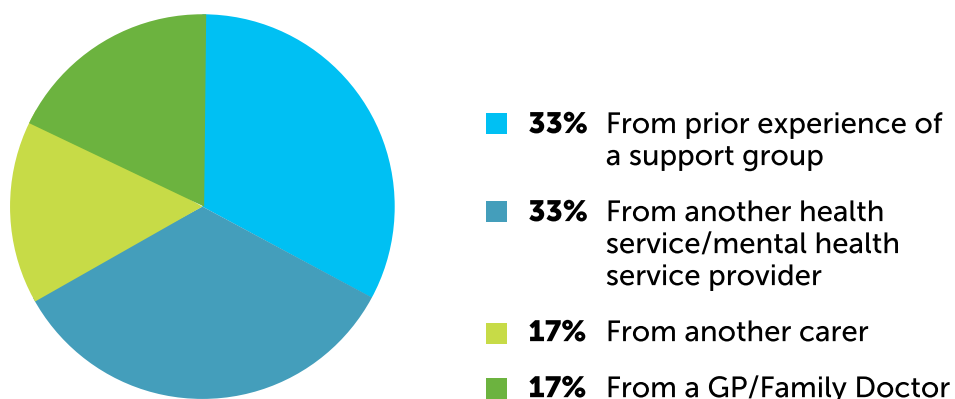

ACCESS AND EXPERIENCE OF SUPPORT

The following survey results are reported to reflect participants' involvement and experience of peer support, informal support and formal support.

Peer Support

Only a minority (16.0%) of participants were members of a carer's peer support group and all of these belonged to one group that met in Warrnambool—Wattletree Carers Group—although members travelled from all five GSC Local Government Areas (LGAs) to attend the group meetings. As outlined previously, this group was known to the researchers, and group members had received direct information about the project via a presentation at their meeting.

Of the small number of participants attending a peer support group, most had heard of the group via prior experience or from a health/mental health provider (see Figure 10). Participants communicated an overwhelmingly positive response to being a member of a peer support group, with one third (n=2) saying that the support group 'always met their needs as a carer', and those remaining describing the group as 'often meeting their needs as a carer'.

Figure 10: How participants learned about a peer support group (N=6)

- **33%** From prior experience of a support group
- **33%** From another health service/mental health service provider
- **17%** From another carer
- **17%** From a GP/Family Doctor

Formal Support Services

Only 10 participants (21.3%) (see Figure 11) identified as currently accessing any formal carer support services. Of those reporting on their access of formal services, the majority received information about the service via another health or mental service provider or as an outcome of previous experience (see Figure 12). This suggests that people only learn about the availability of formal services once they are involved in the health system. This raises the question as to whether carers are involved in mental health care planning (alongside the person they are caring for) or left to find their own way in the system. Carers may benefit from knowledge about available services at an earlier stage, for the wellbeing of themselves as well as those they are caring for.

Figure 11: Participants currently accessing any formal carer support services (N=47)
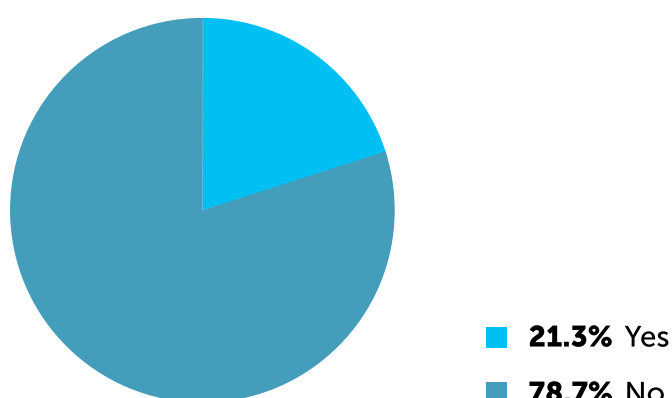

- **21.3%** Yes
- **78.7%** No

Figure 12: How participants learned about available formal carer support services (N=9)
(Please note, participants could list multiple information sources)

- From another carer
- From a GP/Family doctor
- From another health service/mental health service provider
- From prior experience (e.g. previous work in the health field, previous caring role)
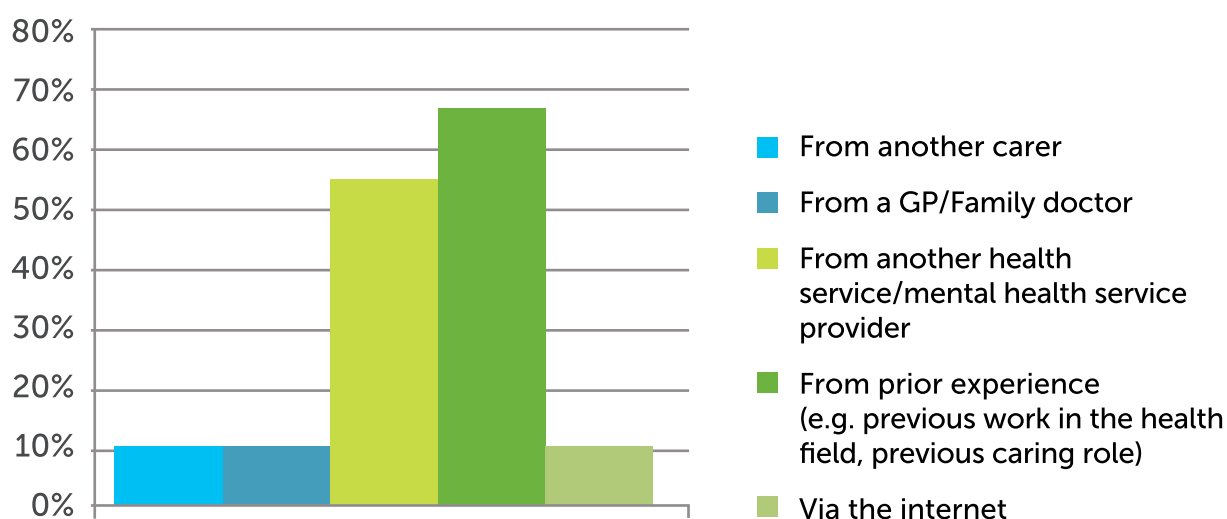- Via the internet

Figure 13 outlines the nature of the services currently being accessed by nine of these 10 participants. Additional services listed as options in the survey but not currently being accessed by participants included:

- In-patient mental health care for myself
- Alcohol and other drug (AOD) carer support services
- Financial services
- Transport services.

The great majority of formal services accessed were public mental health services and mental health community support. Given the small number of people who were accessing services (n=9), it is important to note that these people were accessing multiple service types.

Figure 13: Type of formal support services currently accessed by participants (N=9)
(Please note, participants could list multiple service types)

- Public Mental Helath Services (carer consultant, carer peer workers)
- Mental health community support
- In-patient mental health care for the person I am cring for
- Respite services in the home
- Home services support (cleaning, cooking, gardening, etc.)
- Telephone support
- Online support
- Respite services outside the home
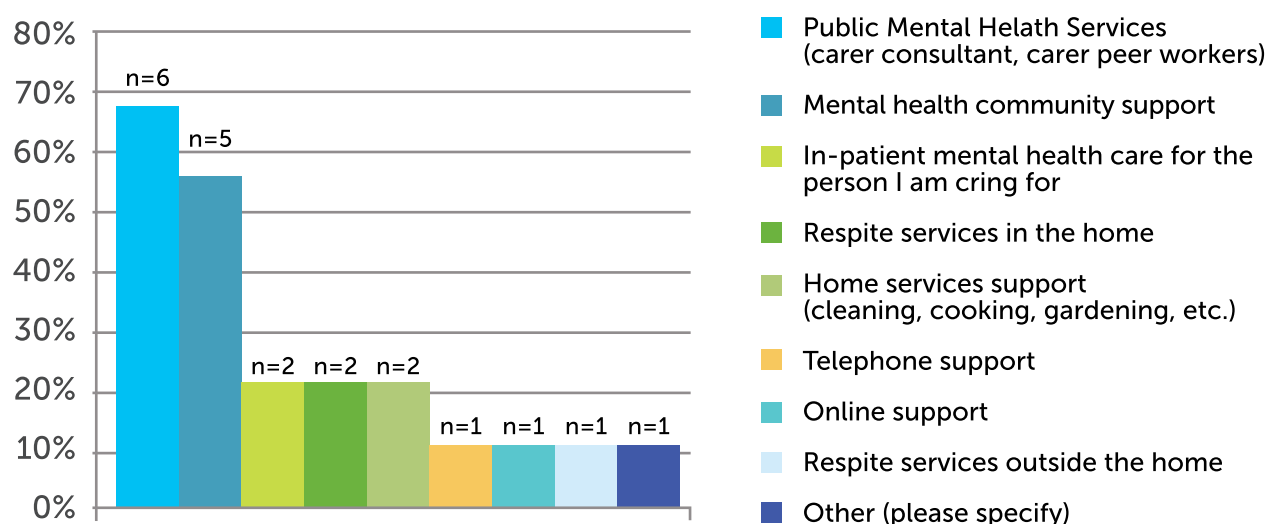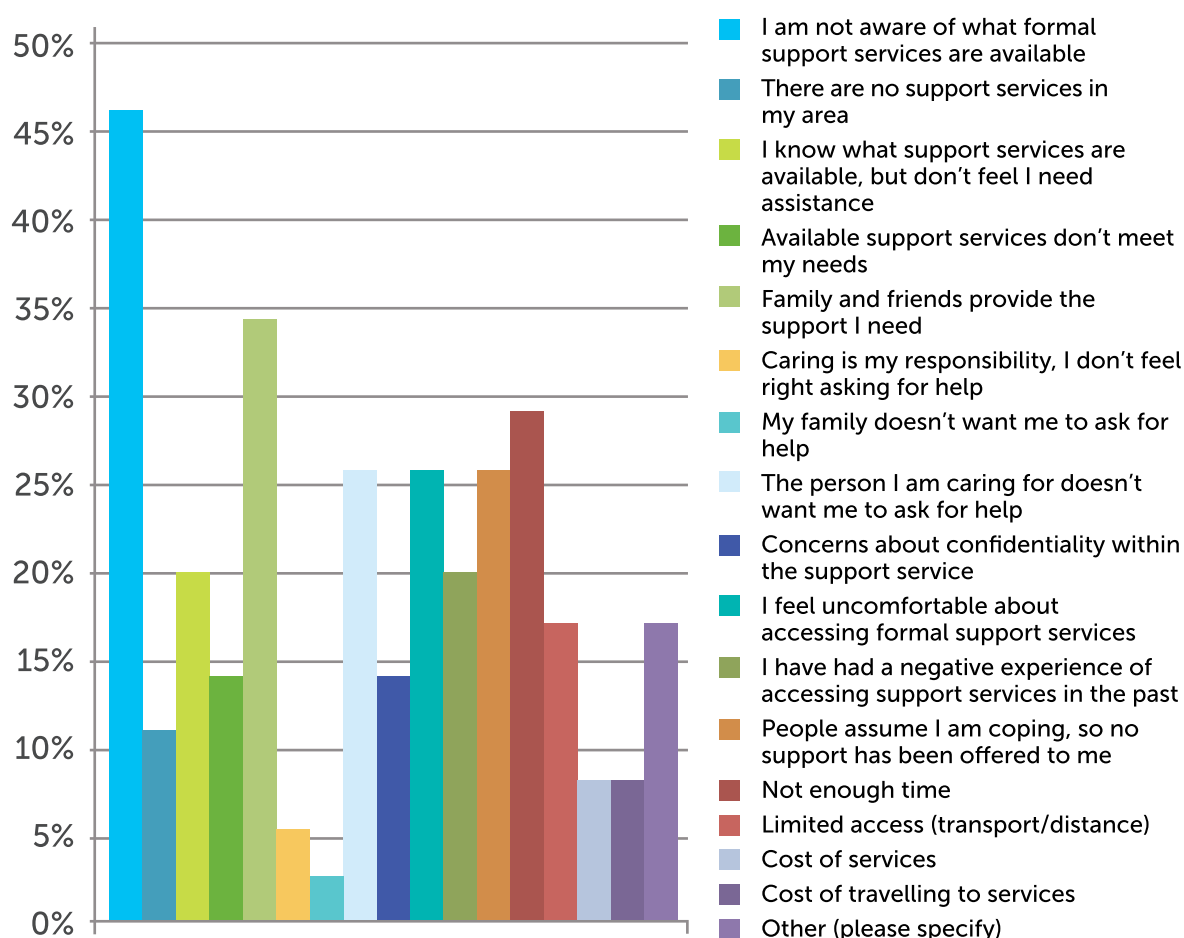- Other (please specify)

Figure 14 identifies the range of reasons for participants not accessing formal support services. Participants generally expressed several reasons why they did not utilise formal support. Almost half of all participants were unaware of what formal support was available to them. One third of participants accessed informal family support rather than use formal support services. Numerous participants expressed reasons reflective of the stigma of poor mental health including not wishing to ask for help (themselves, other family members or the person they are caring for) and feeling uncomfortable about seeking support. Almost one third of people stated that lack of time limited their ability to access formal support.

Figure 14: Reasons for not accessing formal support services (N=35)
(Please note, participants could choose multiple reasons
for not accessing support)

- I am not aware of what formal support services are available
- There are no support services in my area
- I know what support services are available, but don't feel I need assistance
- Available support services don't meet my needs
- Family and friends provide the support I need
- Caring is my responsibility, I don't feel right asking for help
- My family doesn't want me to ask for help
- The person I am caring for doesn't want me to ask for help
- Concerns about confidentiality within the support service
- I feel uncomfortable about accessing formal support services
- I have had a negative experience of accessing support services in the past
- People assume I am coping, so no support has been offered to me
- Not enough time
- Limited access (transport/distance)
- Cost of services
- Cost of travelling to services
- Other (please specify)

Despite low rates of accessing formal support services, Figure 15 demonstrates that outcomes were generally positive when these services were accessed. Of nine participants responding, two described their needs as 'always' being met, four as 'often' being met, while three participants described their needs being met 'sometimes' by accessing these formal support services.

Figure 15: Frequency of formal support services meeting participants' needs (N=9)

Legend:
- Always
- Often
- Sometimes
- Rarely
- Never
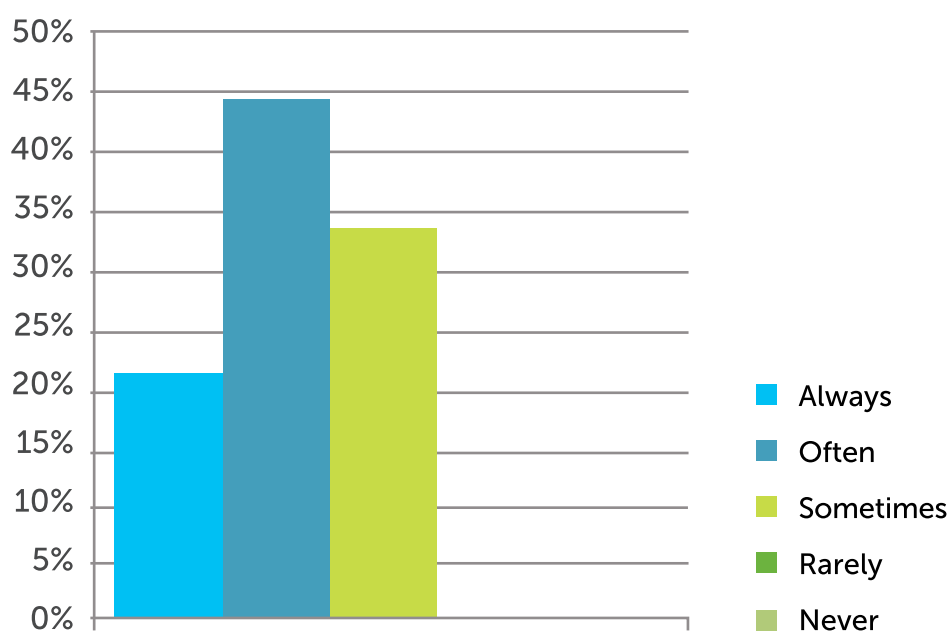
Informal Support Services

Significantly more participants (54.3%) were currently accessing informal carer support from family or friends, when compared with those accessing formal support services, as indicated in Figure 16.
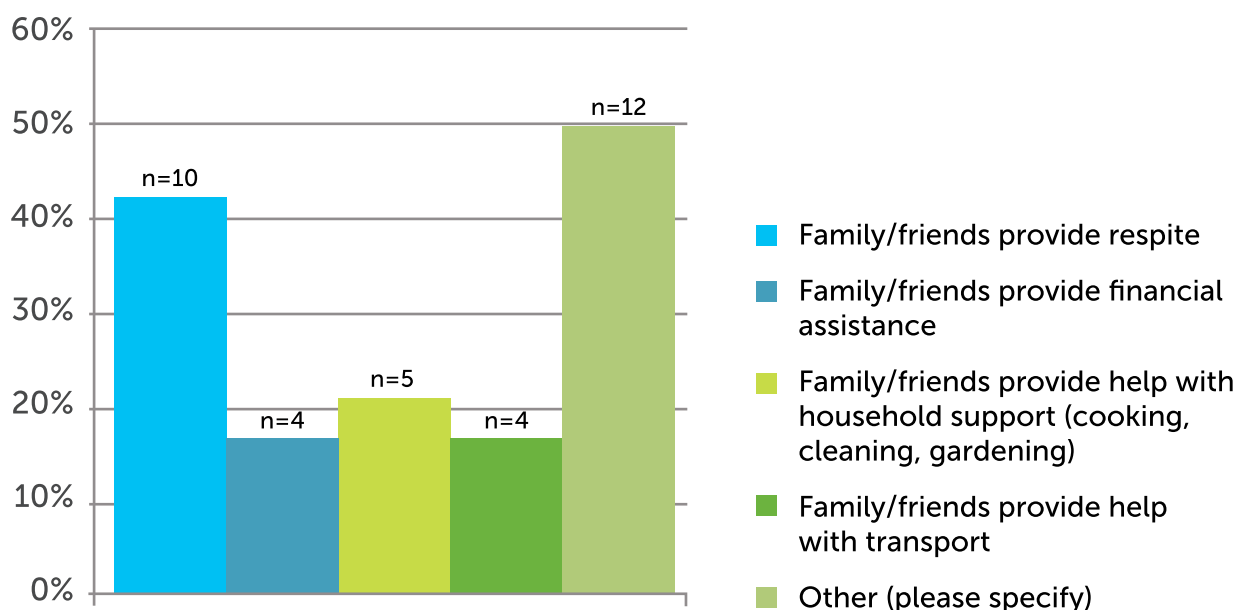
Figure 16: Participants currently accessing any informal carer support from family and/or friends (N=46)

- **54.3%** Yes
- **45.7%** No
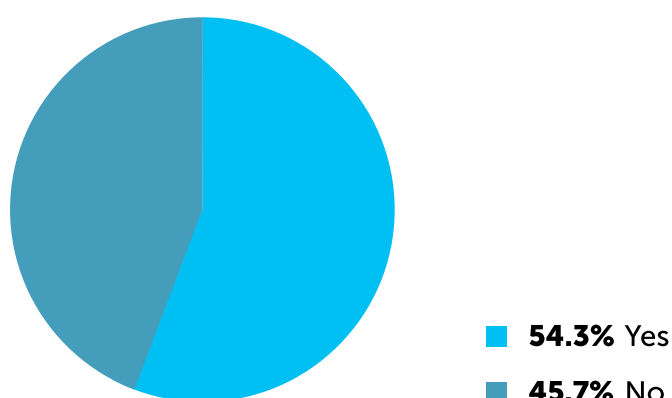
There was a range of tasks that family and friends assisted with (as outlined in Figure 17). Over 40% of participants described this support as including assistance with respite. In the 'other' category, participant's responses generally focused on the opportunities to talk and be listened to by family and friends, and the emotional support and therapeutic benefit that came from this.

Figure 17: Type of informal support currently accessed by participants (N=24)
(Please note, participants could list multiple service types)

Legend:
- Family/friends provide respite
- Family/friends provide financial assistance
- Family/friends provide help with household support (cooking, cleaning, gardening)
- Family/friends provide help with transport
- Other (please specify)

Participant Self-Care

Almost three quarters of participants participated in some regular activities with other people for their own enjoyment or personal benefit, as detailed in Figure 18. However, when examining these activities in detail (see Figure 19), they were more likely to be of an informal nature, and less likely to need the regular commitment required by activities such as sporting teams and service clubs. This was made particularly clear when looking at the 'other' category which included activities such as having coffee, watching sport on TV, shopping, bushwalking, horse riding and informal music sessions.

The reported rates of volunteering amongst participants—emergency services (2%) and other service clubs (6%)—were low compared to the 2011 Census rates for formal volunteering in Warrnambool (29.9%) (9). Once again, this represents participant's inability to involve themselves in activities on a regular basis.

Figure 18: Current participation in regular activities WITH OTHER people for carer's own enjoyment or personal benefit
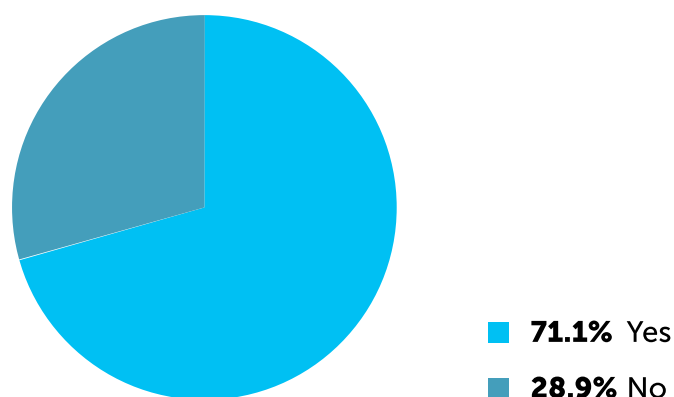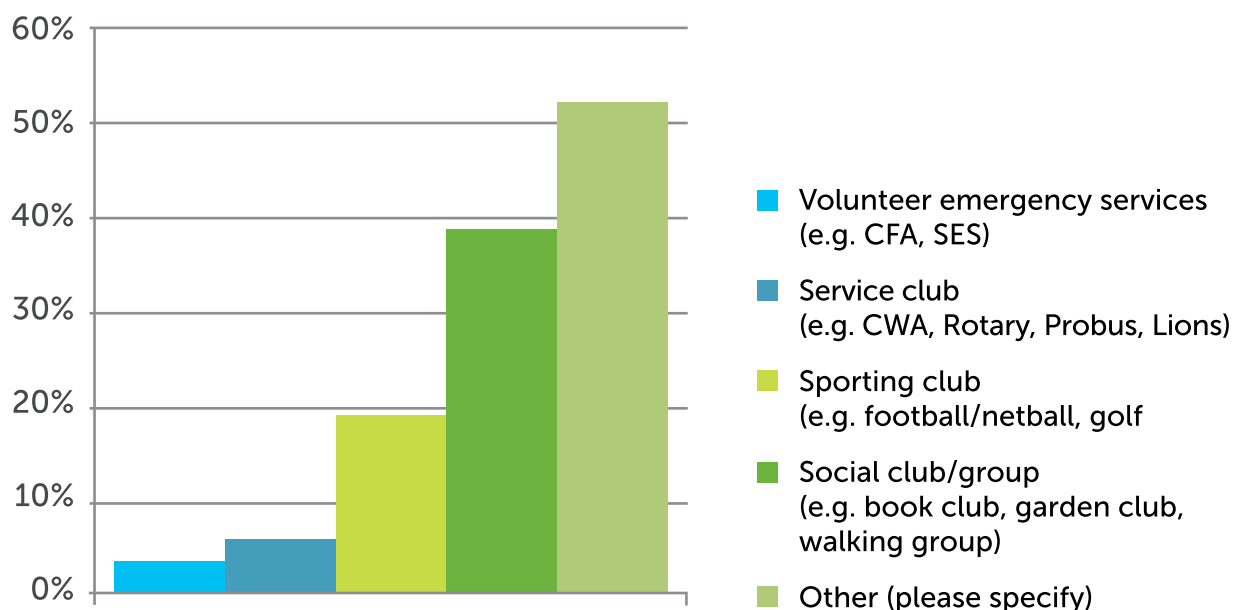

- **71.1%** Yes
- **28.9%** No

Figure 19: Participant activities with OTHER PEOPLE for enjoyment or personal benefit (N=31)
(Please note, participants could select more than one activity)

Legend:
- Volunteer emergency services (e.g. CFA, SES)
- Service club (e.g. CWA, Rotary, Probus, Lions)
- Sporting club (e.g. football/netball, golf
- Social club/group (e.g. book club, garden club, walking group)
- Other (please specify)

Participants were more likely to engage in activities for enjoyment or personal benefit on their own, than with other people (compare Figure 18 and Figure 20). These solitary activities were both inside and outside the home. 17 of the 39 participants described reading as one of their activities. Getting outside into the garden was described by several participants, as were other outdoor activities such as going for a drive or going to take photographs. Other activities included efforts to keep physically active, such as walking the dog, swimming, tai chi, golf and going to the gym. Music played a significant part in several participants' self-care routine—including singing, listening to and playing music.

Figure 20: Current participation in regular activities ON THEIR OWN for carer's enjoyment or personal benefit (e.g. go for a walk, read the newspaper

- **87%** Yes
- **13%** No
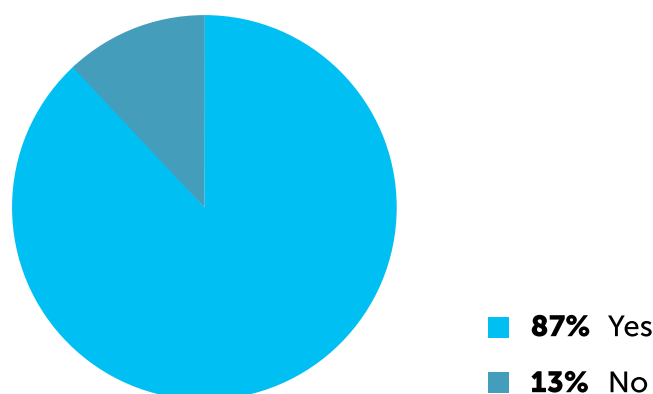
QUALITATIVE THEMES

Analysis of the qualitative data identified six key themes. These included 'time', 'navigating the complex roadmap of caring', 'the role of family and friends—for better or worse', 'personal loss and growth, personal doubt and acceptance', 'who cares for the carers?' and 'I need to talk and I need someone to listen'. Each theme will be explored in turn, supported by exemplar quotes from participating carers.

TIME

Time—or lack thereof—was a key factor for all participants. Caring for someone with a mental health condition can be an all-consuming commitment—taking time and constant personal effort—and required participants to make sacrifices in many areas of life.

> *It is life consuming being a carer. I don't have a minute in my day to myself. My friend consumes the majority and what time I have left in the day goes to my family. (#18)*

Participants often felt that the level of commitment required was not always understood or acknowledged by others:

> *A huge challenge for me was that many people don't understand and aren't aware of the constant state of stress and worry you are always in and not being able to fully concentrate on work tasks because your mind is elsewhere. Being a strong person all the time, because you feel you have to be, is extremely exhausting. (#42)*

Finding people that understood how complex the caring process could be was often challenging. One participant described her unmet need as follows:

> *Someone who understands mental health properly and the complexity of care to support those living with it. People don't understand how difficult it can be. (#1)*

The constant and unrelenting nature of the caring role meant that participants developed a deep insight about the effect that poor mental health had on the person they were caring for. This depth of understanding was not necessarily held by those on the outside of the relationship, leading to misperceptions and doubt. As one participant explained:

> *My husband is a shell of the man he used to be. That's one of the hardest things, also as he comes across OK in short bursts, unless you spend some time with him you don't realise the extent of this debilitating illness. Getting people to believe he's as sick as he is has been really hard. (#21)*

Finding time to effectively achieve the tasks of everyday living could be a challenge for participants. One participant explained the effect on their ability to balance work and caring demands:

> *I have to limit my working hours to 30 per week as mentally it's too draining caring for someone at home and others in my work. Even then it's a stretch sometimes but financially it's difficult to survive if I don't. (#22)*

Time pressures also affected carers' abilities to care for other family members:

> I am working full time and have family members assisting me to do that. I then take the responsibility of doing the caring for my teens once I get home and on weekends. I feel it's important to be available for my children to assist them with their mental health issues/successes. (#3)

Another participant explained the effect of time pressure on managing diet:

> I am obese but do not get the time to eat healthily as we live on fast food & microwave meals which are quick (#48)

The time required for caring duties, in addition to the demands of work and family life, meant that people felt stretched and challenged to find extra time to negotiate any opportunities available for formal support services, informal support, leisure time for themselves and time for their own self-care. One participant listed the demands on her time as follows:

> Time Factor/ Mother to 5 children/Also carer for elderly mother who resides in same home/children activities list goes on!! (#12)

Another participant listed a range of personal opportunities she had given up as a result of her caring obligations:

> Much of my time. Other relationships. Mental headspace. Time for me. Time for my son as a parent. My own aspirations. (#25)

Where carers were able to fit in some personal time, their activities were opportunistic and limited to things that did not require a regular commitment or forward planning. Carers were consistent in their desire for more personal time. As one carer explained:

> It is hard to do anything on a regular basis due to carer demands so I tend to try & do things when i can which isn't as often as I like. I cannot commit to anything regular as carer because I never know when I will need to stay at home & look after my family […] I swim as much as possible with a friend, try & meet up with friends when I can & enjoy cycling & walking when I can but I would like to be able to do more & join clubs. I'd love to do yoga & learn a musical instrument but we have a 5yo (year old) who can be quite demanding & my wife often struggles with some of his behaviour being constantly tired & often unmotivated. I tend to have to do most of the housework & get irritated & resentful. (#48).

For this participant, lack of time inhibited his ability to care for himself and to explore care options for his son.

> I feel my son will also pick up this & it will increase his anxiety. He has behavioural support at school & a CAMHS referral has been suggested but I don't want him being labelled or given medication & I don't have time to take him anyway. I feel stuck between a rock & a hard place. (#48)

The constant demands of caring meant that planning ahead—an example given by one participant was planning a holiday—and "making big commitments"(#50) were not possible for many participants. Although participants recognised the need for self-care, finding time to do this was often challenging. A small number of participants described being actively involved in group activities such as service clubs, sporting clubs, book groups and walking groups. For many people this was not possible, as described by one participant:

> "[I have] no real time to do so (regular activities with other people) with everything else going on". (#1)

For most people, activities with others were replaced with solo self-care and leisure activities commonly including walking or running (alone or with a dog), going to the gym, gardening, reading, craft, listening to or playing music and other forms of exercise.

In summary, the time commitment of caring was significant, affecting people's work and family life and reducing opportunities for self-care and the care of others, as well as leisure time and social connection.

NAVIGATING THE COMPLEX ROADMAP OF CARING

Carers described navigating the complex roadmap of caring a challenging process. Within this theme, participants recognised that there was no 'one size fits all' solution to support, but highlighted the 'red-tape' associated with a mental health condition and limited knowledge meant that receiving effective and adequate support—for those they were caring for as well as themselves—could be challenging. Each of these subthemes will be discussed in turn.

The complex and varied nature of people's needs meant that there was unlikely to be a 'one size fits all solution' for carers or those they were caring for. One participant explained their needs in the following way:

> Someone who understands mental health properly and the complexity of care to support those living with it. People don't understand how difficult it can be. (#1)

Navigating the system of caring was complicated by the 'red tape' faced by participants. As one participant explained:

> [My most unhelpful support has been]"The system" ie Centrelink, etc with all the 1000s of forms you need to complete. (#33)

> It is hard enough caring for someone else without having to spend hours trying to find agencies etc that can help you…there must be an easier system of locating who in your area can help you as a carer. (#33)

Different cultural backgrounds impacted carer's needs and their subsequent ability to find appropriate support. While there were only two participants identifying as Aboriginal or Torres Strait Islander background, the cultural heritage and traditions played a significant role in the experience and perceived needs of these carers. As one explained:

> It's a really difficult time and much more support and services need to be provided especially specific to the treatment and care of Aboriginal people such as Healing Centres that are regionally based as most Koori people like to be near their people and their Mob. (#52)

Who was being cared for presented an additional layer of complexity. Caring for a child with a mental health condition required a unique range of support services, with several participants describing their access of specialised youth services, such as Headspace, as helpful in this situation.

> *[My most helpful support has been] being able to talk to my brothers counsellor at headspace about where he is at. (#28)*

Frustration was exhibited by the perceived failure of services to meet these unique needs, particularly when it came to the caring of children with a mental health condition. This was particularly the case with formal services. More than one participant expressed the difficulties accessing services, as explained:

> *[I had] a 3-4 month wait time to see a psychiatrist when I had a suicidal 8 year old. (#10)*

> *[I need] more access to qualified one-on-one professionals in adolescent mental health. (#4)*

Some participants acknowledged the inability of existing support services to cover all carers' needs—despite good intentions—and the resulting lack of effective support available to them. As one participant described:

> *Wellways [was my most unhelpful support] although prob (probably) out of their hands due to lack of government funding. Barwon south west carers support, their focus is more on aged care and no doubt they have limited funding from government also. I understand this and I'm grateful for what these organisations have done to try and assist. I'm sure there are many family's who have a need that is greater than ours also. (#22)*

Participants described conflicting and inconsistent experiences when accessing formal support—with some carers identifying these as 'helpful' (at least to some degree), and others describing formal services as their 'least helpful source of support'. A particular example relates to inpatient care. One carer described Ward 9 (inpatient facility) at SouthWest Health Care as their least helpful experience of support. It is possible that this was a reflection of a single episode or personal experience, rather than a systemic or entrenched issue, as other participants reported the opposite experience. As stated by the latter participant:

> *I would also like to add that South West Health Care services offer outstanding service and care for their patients. (#42)*

The inconsistent reporting of what constituted 'most helpful' and 'least helpful' support reflected the complex and varied needs of carers. Common examples of support listed as 'most helpful' included Headspace (#13, #26, #28) and counselling (#15, #25). Online support was also seen as a helpful complimentary support option, although not always sufficient on its own (#33, #25).

Support—either formal or informal—was often seen as helpful when the provider of the service had "the right personality"(#37) as indicated by demonstrated empathy and understanding. One participant described their most helpful support as:

> *Barwon Health Carer Support - someone to listen to me as a carer. (#5)*

Another participant described their local GP clinic (where there is potential to have ongoing contact and connection) as:

…providing exemplary support above their normal roles. (#40)

In contrast, least helpful support was often described in the context of support providers failing to demonstrate empathy or understanding of the situation. Contrary to GP's previous being described as the most helpful support, when GP's were not seen as understanding and supportive, this service was described as the least helpful source of support for participants:

General Practitioners - lack of understanding about mental health. (#1)

It is just so hard and heart breaking when you don't get the support for the family member from their local GP. (#17)

Complicating carer's navigation of the roadmap to support was a lack of knowledge of what support was available. This was sometimes overtly stated, as explained by this participant:

I am not aware of what formal support services are available. (#10)

Another participant faced a similar challenge, as explained:

(I have a) lack of clear knowledge of supports when accessing supports in (my) local area. (#25)

Other participants appeared not to have identified any services in their local area, as explained by this carer:

There are no support services in my area. (#2)

While this may not accurately reflect the availability of support, the perception of no support is equally important.

Knowledge about the availability of support for carers (and people they are caring for) was greatest in participants who had previous caring experience or who worked in the health sector. However, despite significant personal experience, even these participants faced challenges when seeking appropriate support. As one women who had both work experience and experience as a carer explained:

I work as a personal support carer […] and have cert 4 in mental health and disability. My work place has been very supportive and provided some in home respite for my daughter who also has MS. We accessed Headspace when she was 17 and now use Saint John of God (SJOG) community mental health services who also provide family support, this organisation is an excellent service. South west health service mental health do not provide enough support for families. When my daughter was having an acute manic episode I took a week off work to care for her as I was unable to get her an acute care hospital bed at the time. My workplace also put in extra assistance during this period to support our family. Eventually when my daughter had a depressive episode I was able to get an acute bed for two weeks in south west mental health services. This was not the best place for her at the time as there were patients in there with psychosis but it was all that was available to give myself, spouse and her sister a break. Now that we have a long overdue step up step down facility on Moore St I'm sure families will be better catered for. It was a difficult time for us and continues to be sometimes. Had I not had the ability to advocate for myself and the support of SJOG mental health clinician Mark Powell advocating for my daughter and family also I'm not sure what I would have done. (#22)

Although carers participating in the survey rarely mentioned the National Disability Insurance Scheme (NDIS), uncertainty about how effectively it would deliver its aims of 'tailored care' appeared to add to the perceived complexity of navigating the roadmap of caring into the future. As explained by one participant:

> *[I need] regular out of home appropriate respite for my daughter to increase her independent living skills. Hopefully this will happen when NDIS kicks in in our region. Although I wonder if the government has allowed enough funding per person to employ people with qualifications to work with clients. I'm not confident with what research I've done so far that this is the case. Also the quality framework legislation for NDIS to ensure people are cared for properly under NDIS appears to have been rushed and lacking detail. (#22)*

In summary, navigating the roadmap of caring proved to be a complex and challenging process for the majority of participants. These perceptions of complexity were contributed to by red tape, culturally specific needs, lack of knowledge or information, the specific needs of the person they were caring for, past experiences of caring and support seeking and anticipated future support seeking experiences.

THE ROLE OF FAMILY AND FRIENDS—FOR BETTER OR WORSE

The role of family and friends and their provision of informal support had a polarising impact on the carers participating in the survey. Many carers described friends and family as providing invaluable assistance on a range of levels. This included assistance with practical household tasks, as described here:

> *Family/friends provide help with household support (cooking, cleaning, gardening). (#44)*

Others described family and friends as assisting with caring duties, as described here:

> *Family and friends provide respite and help with transport. (#3)*

> *Family/friends provide respite. (#6)*

Still others described the emotional support that was offered by family and friends, as exemplified here:

> *[Friends and family provide a] sounding board - emotional support when I am struggling. (#38)*

On the whole, it was the informal support—frequently offered by friends, family and other carers—that was identified by participants as their most helpful source of support:

> *Family and friends provide the support I need. (#8)*

Family and friends with a shared caring experience—and therefore, a shared understanding of the caring experience—were frequently described as providing positive support:

> *My friends are fellow carers so they are always supportive (#46)*

> *[My most helpful support is]...other carers (#43)*

Contrary to this experience, a small number of participants identified their friends and family as both their most and their least helpful form of support (#12 and #14). When family and friends were identified as unhelpful, this was generally the result of conflict or lack of demonstrated empathy:

> *My wife's family do not get on with us & we often argue. They are not very sympathetic to our struggle & keep saying we should just get on with it. (#48)*

> *[My most unhelpful source of support has been] peers/colleagues with minimal understanding or empathy, my mother. (#42)*

In summary, while the majority of carers described utilising the informal support provided by friends and family, it can't be assumed that everyone has a positive support network. Carers expressed a range of positive and negative experiences—sometimes both.

PERSONAL LOSS AND GROWTH, PERSONAL DOUBT AND ACCEPTANCE

Similar to the experiences of informal support from family and friends, the impact of caring on individuals was fraught with contradictions. Although faced by necessary sacrifices and personal loss, the caring role also led to personal growth. Similarly, carers expressed personal doubt about their ability to effectively care for someone with a mental health condition, yet also demonstrated an acceptance of themselves, and their ability and capacity as carers. These contradictions will be explored in the following paragraphs.

The personal loss associated with an intense caring role could be significant for participants. Giving up "my hopes and dreams"(#48), "my freedom"(#45), "peace of mind"(#44 and #4), "routine and balance"(#42), "time to myself" , "career and marriage" (#36) and "a life"(#43), and "relationships, future goals – career"(#1) were some of the sentiments shared.

Opportunities that are often taken for granted by many in society were also unavailable to some carers. For example, the idea of having a relaxing and restoring family holiday was not always possible. As one participant explained:

> *I cannot go away for long periods and we struggle with holidays which are really no different from being a carer at home, just in a different place. (#18)*

Other carers described challenges to maintaining social connections:

> *I have been unable to maintain a positive social life—seeing friends, going away for a weekend, etc. (#3)*

> *I withdrew and became isolated—so I gave up contact with some friends. (#14)*

Loss of relationships could be with friends, as described above, but also with the person they were caring for. One participant, who was caring for her spouse, described the loss of that relationship:

> *[I have lost] being a wife. I've lost my husband, lover, friend. (#20)*

This loss could also extend to other members of the family, as several participants described:

> *[I have lost] precious moments with my kids. (#18)*

> *[I have lost] time for my son as a parent. (#25)*

In the extreme, the loss associated with the challenges of caring extended to personal health and wellbeing. As one participant caring for his mentally ill spouse described:

> *Sometimes I just cry but again cannot let them (family) see me so I bottle it all up & it affects my physical & mental health as I have diabetes, high blood pressure & cholesterol & have had heart investigations for angina & an irregular heart beat & for an unexplained loss of consciousness when i collapsed in the street & had to be resuscitated as I had swallowed my tongue & was taken to hospital & kept overnight for observation. I have a sleep apnoea & worry I may die early but again I keep it to myself as I can't worry anyone else. I really do not know what else to do but just keep dragging myself though each day at a time not knowing if I will wake up the next day. (#48)*

One participant described their own experience of a "mental health disorder" (#18) as a result of their caring responsibilities. Another described "higher stress levels, increased anxiety (#20).

It is important and heartening to stress that caring was not an entirely negative experience, with all participants able to include examples of personal growth and benefits from their caring role. These areas of growth were experiences that may be difficult to quantify, but were expressed by many participants. These gains were described in several areas, including increased knowledge and awareness, as follows:

> *[I have gained] awareness for mental health issues in those around me - ability to identify and react accordingly. (#42)*

> *[I have gained] knowledge, experience, managing skills. (#5)*

> *[I have gained] better understanding of mental health issues. (#9)*

> *[I have] learnt a lot about medical profession and what services are available. (#13)*

Others described a growth in empathy and their relationships with others, as follows:

> *[I have gained] understanding, compassion and empathy. (#50)*

> *[I have gained] compassion, knowledge and new friends. (#45)*

> *[I have gained] tolerance, acceptance. (#43)*

> *[I have gained] insight into mental health symptoms and treatment. (#35)*

This combined knowledge and empathy sometimes translated to a greater willingness and desire to assist others experiencing similar challenges. As described:

> *[I have gained] willingness to support others. (#26)*

The growth in relationships with others was often reflected in changes to the relationship the participant had with the person they were caring for, as several participants explained:

> *[I have gained] a stronger relationship with my husband. (#41)*

> *[I have gained] a better relationship with my partner. (#6)*

> *[I have gained] my daughter's trust - she has opened up a lot about her concerns. (#38)*

> *[I have gained] a closer relationship with my son. (#13)*

> *[I have gained] a deeper level of understanding, love and patience for my partner and empathy towards others. (#14)*

Growth in personal strength and character was also described by several participants, as follows:

> *[I have gained] strength of character, resilience. (#42)*

> *[I am] personally stronger. Standing up for one self. (#12)*

> *I feel I have grown emotionally as an adult. (#33)*

Sometimes this personal growth led to an increase in confidence. As one participant described:

> *[I have gained] knowledge! Patience! Self-awareness and confidence. (#3)*

Occasionally, participants saw recognition of this growth reflected in other's perceptions of them. As one participant explained:

> *[I have gained] respect from other people that are not carers. (#21)*

However, this was rare and most of the growth participants described was in how they saw themselves, rather than how they perceived others saw them.

Some participants continued to struggle with self-doubt that left them questioning the value and limitations of their support—despite contributing long hours and great effort into their caring role. They were left "not always knowing if you are helping in the right way" (#52). This lack of certainty led participants to wish for "guidance on the best way to act and respond, including the most appropriate language to use and saying the right things" (#42). This was no doubt made more complicated by the episodic and sometimes unpredictable nature of living with a mental health condition. As one participant explained:

> *I now have a constant state of low level anxiety and guilt that I can't do more. (#39)*

Occasionally, participants described being able to manage this doubt and achieve a level of "acceptance" (#43) of their abilities, their limitations, their role as a carer and all that came with this challenge. As one carer explained:

> *I have reached a limit to what I can do to help and I am ok with that. (#31)*

In summary, carers experienced a diverse range of emotions and internal conflicts in their role as carers. All carers were able to describe significant (but often difficult to quantify) personal gains from the caring experience, but this was never without accompanying loss and was sometimes accompanied by self-doubt. This reinforces the need to understand the complexity of the caring role, both practically and emotionally.

WHO CARES FOR THE CARERS?

As highlighted in the report so far, the caring role can be a difficult and draining one and carers need support for their own health and wellbeing—something well recognised by the carers themselves. One participant explained this particularly clearly:

> *It is a full time job and I take it seriously because my loved ones trust me and chose me to help. I realise I need to take care of my own wellbeing though to be any real help. It's important to have friends and support otherwise you can easily feel overburdened and isolated. There are also crisis times when professional help needs to be utilised as I may be too close to the situation to help. (#50)*

Another explained the consequences of poor self-care:

> *Carers lose sight of themselves and can become unwell physically and emotionally. Carer support is vital (#46)*

Making time and space for self-care in an environment where participants caring role often went unrecognised or unacknowledged proved challenging, as one carer explained:

> *A huge challenge for me was that many people don't understand and aren't aware of the constant state of stress and worry you are always in and not being able to fully concentrate on work tasks because your mind is elsewhere. Being a strong person all the time, because you feel you have to be, is extremely exhausting. (#42)*

The remainder of this section will outline some of the needs expressed by carers as a way of supporting their own health and wellbeing.

Numerous participants spoke about the importance of improving respite services. As expressed by these examples:

> *The biggest issue I think is lack of suitable out of home respite for families on a regular basis to give them a break. (#22)*

> *More respite. There is not enough respite for carers. (#21)*

> *There needs to be much more crisis accommodation facilities and respite services to give families a well earned break. (#52)*

Respite was particularly important as a way of relieving the constant, all-consuming demands of caring, as described previously in this report. As reinforced by this participant:

> *[I need] respite, it is stressful to have to be on suicide watch of your brother at times. (#28)*

Appropriate respite was seen as having dual benefit—for both the carer and the individual living with a mental health condition. Providing assistance and training (via respite) for people with a mental health condition, had indirect benefit for carers as well. As one participant explained about the needs of her daughter:

> *[I need] regular out of home appropriate respite for my daughter to increase her independent living skills." (#22)*

It appeared that some participants had previous experience of successful respite, but that this was no longer available. As explained by one participant:

> *Respite was my lifeline. NIL funding now for it. (#46)*

At times, the need for a break meant that participants felt compelled to choose respite care options that were not ideal for the wellbeing of the person they were caring for. As one participant explained:

> *Eventually when my daughter had a depressive episode I was able to get an acute bed for two weeks in south west mental health services. This was not the best place for her at the time as there were patients in there with psychosis but it was all that was available to give myself, spouse and her sister a break (#22)*

Many participants support focus was on caring for their mental health, whether that be through peer support from other carers, better information transfer or professional/formal mental health support. One participant described a need for improved information to assist the mental wellbeing of carers:

> *[We need] more information for carers about what can help us take some of the stress off of our shoulders (#6)*

Another participant described a desire for counselling services:

> *I think carers should be entitled to free counselling because we quite often have a lot of emotional issues to deal with. (#33)*

Whether participants had knowledge of government funded psychology services availability to everyone with a mental health care plan (carers and those they care for) was unknown within the limitations of the survey.

Some participants spoke about the need for looking after their physical wellbeing through a focus on diet and physical fitness. As described here:

> *I am mindful of physical health - nutritious food and regular exercise. (#39)*

Other participants spoke about the importance of a holistic approach to wellbeing, encompassing the need for care of not only the carer and the individual they are caring for, but for the broader family unit affected by the situation. As detailed by this participant:

> *[I need] sibling support. Not just access to parent support via public mental health services. I am passionate about having support for a family unit as a whole. I would like to see sibling support included in the recovery of a child with major mental health issues. Everyone's world changes when a child is unstable and unable to guarantee their safety. It takes a village to assist that child to learn, function, grow and develop healthy coping and self-care behaviours. (#3)*

Carers spoke about their need for recognition and understanding of their role as carers:

> *[What's needed is] recognition of the carers role. (#43)*

Further detail about the need for recognition was provided by another carer:

> *It's important to care for ones self also otherwise you are unable to care for others. I have to limit my working hours to 30 per week as mentally it's too draining caring for someone at home and others in my work. Even then it's a stretch sometimes but financially it's difficult to survive if I don't. The government needs to recognise the amount of money that carers save by keeping their loved ones in the home #22*

Following on from this need for recognition of their role, was a need for volunteered assistance, as exemplified by these participants:

> *[I need] help even if there is an assumption i am fine…People assume I am coping, so no support has been offered to me. (#28)*

> *People providing assistance without my asking [would be helpful] as I am too proud to request it. (#37)*

This was not unusual given our recognition that while people in rural communities are good at supporting others, they are not good at asking for support themselves.

Potential opportunities for assistance and support were identified as coming from other carers. Sharing knowledge and support opportunities was identified as being of benefit for the wellbeing and self care of other carers. As one participant described:

> [We need to] tell others about 'good' carer support services. (#5)

Other participants explained the value of being able to advocate for other carers:

> [We need to] be a voice more I guess, share realities. (#1)

> [Encourage others to] voice their opinions and have the knowledge that it's ok to push for what you feel you need at that time". (#3)

Other carers suggested that helpful assistance would in the form of practical support such as "home help weekly" (#16), "more money" (#22) and "knowing where to go for support" (#14).

In summary, carers expressed an understanding and desire for improved self-care. Suggested avenues to support this included respite, support for the entire family, support for mental and physical health and opportunities for peer support.

I NEED TO TALK AND I NEED SOMEONE TO LISTEN

Opportunity to express themselves and having someone to listen was consistently reported by participants as being important. This included the empathic ears of friends, family and professionals. As described by one participant:

> The thought that you can't fix some things is awful—that's when you need to hear a reassuring voice. (#38)

The opportunity to have someone take the time and listen—even informally—was seen as very valuable:

> Friends make me a cup of tea and actively listen, allowing me to chat about the difficulties I may be facing (#50)

> (Friends and family provide)…a listening ear to the challenges that our family can face (#10)

Even when participants were missing this opportunity for expression, they demonstrated their desire for it. The following participant explained what would be helpful:

> Someone to talk to, to be open and honest with who will genuinely understand what I am going through as I have felt that I have had no one to cry to if I needed - which is also partly my issue as I internalise most things. (#42)

It was rarely the answer that mattered (answers were frequently not possible), the opportunity to talk and vent emotions was of greater importance:

> Just be there to listen rather than trying to give you answers. (#14)

Listening was equally important on a professional level, with carers urging mental health professionals to listen to them as experts about caring for their loved one. As these participants explained:

> [I need] professionals to truly listen. (#51)

> I think psych service should listen to the carer a bit more about some of the things they do and say. It's why mental health gets a bad name. (#44)

While participants generally described the opportunity for direct communication, the value of being able to talk to someone on a telephone support line was also mentioned (#38).

Increasing opportunity and willingness to talk to about mental health within the community more generally was seen as a positive shift. As explained by this participant:

> *It is great that there is so much more knowledge in the community and people are now talking more and that is a positive thing. (#13)*

In summary, opportunity to talk and have someone actively listen—without necessarily offering a solution—was seen by carers as an important source of formal and informal support.

LIMITATIONS

The scope of this community project did not allow for detailed drilling down to explore differences in carer's experiences based on who they were (for example, caring as a parent or a spouse) and who they were caring for (caring for a child or an older person).

Time limitations meant that the collection of survey data was limited to an eight week period. Further data could have been gathered should this period have been longer. While data gathered was considered to be of high quality and sufficient to meet the needs of this report, permission was given by about one third of participants to make further contact about conducting interviews to gain greater depth of understanding of carer needs and experience. The scope of the community project did not allow for this further follow-up to be undertaken.

RECOMMENDATIONS

A number of recommendations for action have been put forward, based on the findings of this needs assessment:

1. It is common practice to provide carers with written information packs when loved ones are admitted to inpatient care or diagnosed with a mental health condition. Unfortunately, carers are often in a state of high stress, which is not conducive to processing the information contained in this material. Compounding this, the written material comes from a wide range of sources and can be repetitive, confusing and rapidly out-dated. When providing this information, arrangement should be made to follow-up and ensure that the carer understands the material and is aware of opportunities for support. This may require time spent with the carer to read through the material.

2. An additional or alternative possibility to potentially confusing written material could be a peer mentor network to assist carers negotiate the complex requirements of caring. A peer mentor program could pair experienced carers with lived experience of caring—who receive appropriate training and support—with new carers. Mentoring opportunities would provide valuable opportunity for willing carers to provide voluntary support for others, while reducing the stigma associated with new carers seeking support, particularly from someone who may not be perceived as understanding your situation. An appropriately informed peer mentor network could assist in informing carers about available services, financial support, etc., while also providing peer support.

3. Opportunities for support and self-care need to be developed as early as possible in the process of caring for someone with a mental health condition. Linkages to support may be possible when visiting a GP when concerned about a loved one's wellbeing if GPs are educated about the supports available. Ongoing self-care needs to be encouraged. This should not be a one-off process but a process of frequently checking in, in order to engage the carer in appropriate support at times when they are willing and emotionally able to do so.

4. In recognition of the outcome that there is no one-size-fits-all support to suit each carer, individuals need to be encouraged to set personalised goals for self-care and wellbeing, rather than being faced with the generic self-care message of eating healthy, getting exercise, sleeping well. This may include guidance to set personalised SMART goals—Specific, Measurable, Achievable, Realistic and Timely. Examples of SMART goals may be to catch up with a friend for a cuppa once each week, to make an extended appointment with their GP to discuss their own wellbeing needs, to spend 30 minutes each day meditating or practicing mindfulness. It is vital that we acknowledge the individual and varied coping mechanisms of carers and help them to set goals to achieve these, with opportunities to review and build on goal achievement.

5. Respite services (in-home and in-patient services as required) need to be made available to carers. Such services need to be flexible in order to allow for carers to access support dependent on the fluctuating demands of caring for someone with an unpredictable and episodic mental health condition. This may be possible through the utilisation of the NDIS, where support for someone with a mental health condition may include blocks of time away from home (e.g. training opportunities and day services). While not called 'respite', the NDIS includes supports with a 'respite-effect' for carers by providing a break from the caring role. This could potentially (depending on individual needs) include overnight assistance with self-care, assistance in a host family or similar family situation, short-term accommodation in a group residence or specialised home-based assistance. This could have the dual benefit of providing respite opportunities for carers.

6. Given carers who accessed formal services (still only a small number)—for their own wellbeing or the wellbeing of someone they care for—generally found this helpful, there is a need to continue to encourage service access and promote availability. Pathways to accessing care need to be clear and achievable in a timely manner. This may require the development of telehealth or eHealth services to compliment the limited availability of face-to-face services. Initial rapport building (through face-to-face methods if possible) would be important prior to a continued relationship via virtual means.

7. Health professionals (and additionally, other professionals e.g. teachers, service providers whose core business is not mental health but are likely to come into contact with carers) need to be well informed about the services available to support carers. This knowledge needs to reflect the context of rurally based carers, given support designed for metropolitan carers may be inappropriate, ineffective or not accessible for those in rural areas.

8. Carers need to be recognised for the significant contribution they make. This may be in the form of tailored 'care packages' providing personalised messages of support and items to assist with self-care. This could be a service developed by a community volunteer agency in the Great South Coast region (for example, Rotary, CWA, Lions, etc.).

9. Community education and awareness-building about mental health should be maintained and include reference to the lived experience of carers and the crucial role they play in supporting those with a mental health condition.

CONCLUSION

This report captures the voices of 52 people from across the Great South Coast region and provides a clearer understanding of their met and unmet needs as carers of a person with a mental health condition. The project discovered several recurring themes amongst the feedback collected – lack of time, navigating the mental health service sector, the role of family and friends, barriers to self-care and the need to be heard.

The project team was privileged to be given an insight into these carers' experiences, and trusts that the nine evidence-based recommendations in this report will facilitate improved, appropriate and helpful carer support in the Great South Coast.

REFERENCES

1. Pirkis, J., et al., *Who cares? A profile of people who care for relatives with a mental disorder.* Australian and New Zealand Journal of Psychiatry, 2010. **44:** p. 929-937.

2. Dawson, S., et al., *Carers' experiences of accessing and navigating mental health care for older people in a rural area in Australia.* Aging and mental health, 2017. **21**(2): p. 216-223.

3. Hansen, E., et al., *Barriers to the provision of care for people with dementia and their carers in a rural community.* Australian Journal of Primary Health, 2005. **11**(1): p. 72-79.

4. Innes, A., D. Morgan, and J. Kostineuk, *Dementia care in rural and remote settings: A systematic review of informal/ family caregiving.* Maturitas, 2011. **68**(1): p. 34-46.

5. Wenger, G., A. Scott, and D. Seddon, *The experience of caring for older people with dementia in a rural area: Using services.* Aging and mental health, 2002. **6**(1): p. 30-38.

6. Hungerford, C. and F. Richardson, *Operationalising recovery-oriented services: The challenges for carers.* Advances in Mental Health, 2013. **12**(1): p. 11-21.

7. Burgess, P., et al., *Do nations' mental health policies, programs and legislation influence their suicide rates? An ecological study of 100 countries.* Aust N Z J Psychiatry, 2004. **38**(11-12): p. 933-9.

8. National Mental Health Consumer and Carer Forum. *Privacy, confidentiality and information sharing—consumers, carers and clinicians.* 2011; Available from: http://nmhccf.org.au/sites/default/files/docs/nmhccf_pc_ps_brochure.pdf

9. Volunteering Victoria. *Key facts and statistics about volunteering in Victoria.* 2016; Available from: http://volunteeringvictoria.org.au/wp-content/uploads/2016/05/Facts-and-Stats-August-2016.pdf

10. Slade, T., et al., 2007 N*ational Survey of Mental Health and Wellbeing: methods and key findings.* Australian and New Zealand Journal of Psychiatry, 2009. 43(7): p. 594-605.

11. Kessler, R.C., et al., *Lifetime prevalence and age-of-onset distributions of dsm-iv disorders in the national comorbidity survey replication.* Archives of General Psychiatry, 2005. 62(6): p. 593-602.

12. Black Dog Institute. *Facts and figures about mental health*. 2017; Available from: https://www.blackdoginstitute.org.au/docs/default-source/factsheets/facts_figures.pdf?sfvrsn=8.

APPENDIX 1

LEADERSHIP
Great South Coast

'Connecting with Carers in Great South Coast': Carer's Survey

Introduction

We recognise that a carer's role is incredibly valuable, but can also be challenging. This survey has been designed to better understand your needs, as a carer of someone with a mental health condition in the Great South Coast region. Your contribution to this survey is highly valued and we thank you for sharing your experience. Any information you share in the survey will remain anonymous.

The outcome of this project will be a resource (including clear recommendations) that will be presented to the Fight For Your Life working group to actively inform their work in supporting carers of people living with a mental health condition.

If you would like to know any more information about this project, please feel free to contact one of the team members by email:
Leon Carey: sthrncrosskitchens@bigpond.com
Vicki Askew-Thornton: vaskewthornton@moyne.vic.gov.au
Alison Kennedy: alison.kennedy@wdhs.net

<u>PLEASE CONSIDER YOUR ANSWERS AS A CARER OF SOMEONE LIVING WITH A MENTAL HEALTH CONDITION</u>

1. What is your age?

◯ 18 to 24

◯ 25 to 34

◯ 35 to 44

◯ 45 to 54

◯ 55 to 64

◯ 65 to 74

◯ 75 or older

2. Which Great South Coast shire/municipality do you live in?

◯ Corangamite

◯ Glenelg

◯ Moyne

◯ Southern Grampians

◯ Warrnambool

3. What is the main language you speak at home?

[   ]

4. Are you of Aboriginal or Torres Strait Islander descent?

○ No

○ Yes - Aboriginal

○ Yes - Torres Strait Islander

○ Yes - both Aboriginal and Torres Strait Islander

5. What is your current employment/study status (you can choose more than one answer)?

☐ Full time employment

☐ Part-time or casual employment

☐ Not employed but seeking work

☐ Retired

☐ Working as a volunteer

☐ Full time study

☐ Part time study

☐ Unpaid carer

☐ Carer pension

☐ Home duties

6. Has your employment/study status changed as a result of becoming a carer?

○ Unchanged

○ Increased hours of work/study

○ Decreased hours of work/study

○ Ceased work/study

7. How many people living with a mental health condition do you care for?

○ One

○ Two

○ Three

○ More than 3

8. What age is the person(s) you are caring for (you can choose more than one answer if you care for more than one person)?

☐ Under 18 years

☐ 18-24

☐ 25-34

☐ 35-44

☐ 45-54

☐ 55-64

☐ 65-74

☐ 75 or older

9. How long have you been caring for someone living with a mental health condition (combined years of all caring roles)?

○ Less than 12 months

○ 1-3 years

○ 3-5 years

○ 5-10 years

○ 10-15

○ 15-20 years

○ 20+ years

10. Think of the person you have cared for the longest. What is your relationship with this person? They are my.....

○ Spouse/partner

○ Parent

○ Child

○ Friend

○ Other (please specify)

[   ]

11. Do you live with the person you are caring for?

○ Yes

○ No

12. What condition is the person you are caring for living with?

○ Schizophrenia

○ Attention Deficit Hyperactivity Disorder (ADHD)

○ Bipolar Disorder

○ Alcohol and Drug Addiction

○ Depression and Anxiety Disorders

○ Dual Diagnosis (multiple conditions diagnosed)

○ Other

[ ]

13. Are you a member of a carer's peer support group?

○ Yes

○ No

14. If you answered YES to being a member of a carer's peer support group — what is the name of the group?

[ ]

15. If you answered YES to being a member of a carer's peer support group — how did you find out about this group?

○ From another carer

○ From a GP/family doctor

○ From another health service/mental health service provider

○ From a family member or friend

○ From prior experience (e.g. previous work in the health field, previous caring role)

○ Via the media or social media

○ Via the internet

○ Other (please specify)

[ ]

16. Has the peer support group met your needs as a carer?

Always	Often	Sometimes	Rarely	Never
○	○	○	○	○

17. If you answered NO to being a member of a carer's peer support group, please explain why not (you can choose more than one answer if required).

☐ I am not aware of any support groups in my area

☐ Meeting times are unsuitable

☐ Limited access (transport, distance)

☐ Lack of time due to other commitments

☐ I don't feel I need to attend a support group

☐ Concerns about confidentiality within the group

☐ I feel uncomfortable about joining a carer support group

☐ Other (please specify)

[ ]

18. Do you currently access any formal carer support services?

○ Yes

○ No

19. If you answered YES to accessing formal carer support services — what type of support do you access (you can choose more than one answer if required)?

☐ In-patient mental health care for the person I am caring for

☐ In-patient mental health care for myself

☐ Public mental health services (carer consultant, carer peer workers)

☐ Mental health community support

☐ Alcohol and other drug (AOD) carer support services

☐ Telephone support

☐ Online support

☐ Financial support

☐ Respite services in the home

☐ Respite services outside the home

☐ Transport services

☐ Home services support (cleaning, cooking, gardening, etc.)

☐ Other (please specify)

```
```

20. If you answered YES to accessing formal carer support services — how did you find out about this service/s? (you can choose more than one answer if required)

☐ From another carer

☐ From a GP/family doctor

☐ From another health service/mental health service provider

☐ From a family member or friend

☐ From prior experience (e.g. previous work in the health field, previous caring role)

☐ Via the media or social media

☐ Via the internet

☐ Other (please specify)

```
```

21. Has the formal support service/s met your needs as a carer?

Always	Often	Sometimes	Rarely	Never
○	○	○	○	○

22. If you answered NO to accessing formal support services — please explain why not (you can choose more than one answer if required)

- [ ] I am not aware of what formal support services are available
- [ ] There are no support services in my area
- [ ] I know what support services are available, but don't feel I need assistance
- [ ] Available support services don't meet my needs
- [ ] Family and friends provide the support I need
- [ ] Caring is my responsibility, I don't feel right asking for help
- [ ] My family doesn't want me to ask for help
- [ ] The person I am caring for doesn't want me to ask for help
- [ ] Concerns about confidentiality within the support service
- [ ] I feel uncomfortable about accessing formal support services
- [ ] I have had a negative experience of accessing support services in the past
- [ ] People assume I am coping, so no support has been offered to me
- [ ] Not enough time
- [ ] Limited access (transport/distance)
- [ ] Cost of services
- [ ] Cost of travelling to services
- [ ] Other (please specify)

_____

23. Do you currently access any informal carer support from family and/or friends?

- ( ) Yes
- ( ) No

24. If you answered YES to accessing informal carer support — what type of informal support do you access (you can choose more than one answer if required)?

- [ ] Family/friends provide respite
- [ ] Family/friends provide financial assistance
- [ ] Family/friends provide help with household support (cooking, cleaning, gardening)
- [ ] Family/friends provide help with transport
- [ ] Other (please specify)

_____

25. Do you currently participate in any regular activities with other people for your own enjoyment or personal benefit?

- ( ) Yes
- ( ) No

26. If you answered YES to participating in activities with other people — please explain what these activities are (you may choose more than one answer if required).

- [ ] Volunteer emergency services (e.g. CFA, SES)
- [ ] Service club (e.g. CWA, Rotary, Probus, Lions)
- [ ] Sporting club (e.g. football/netball, golf)
- [ ] Social club/group (e.g. book club, garden club, walking group)
- [ ] Other (please specify)

_____

27. If you answered NO to participating in regular activities with other people — please explain why not

[ ]

28. Do you currently participate in any regular activities on your own for enjoyment or personal benefit (e.g. go for a walk, read the newspaper)?

( ) Yes

( ) No

31. Thinking of your role as a carer of someone living with a mental health condition.....

What has been your most helpful source of support?	
What has been your least helpful source of support?	
What could carers and family members do to help improve carer support programs and services?	
What have you had to give up as a result of being a carer?	
What have you gained as a result of being a carer?	
What additional support would be helpful to assist you in your caring role?	
What additional support would be helpful to assist your personal health and wellbeing?	

32. Is there anything else you would like to share about your needs as a carer of someone living with a mental health condition?

[ ]

33. Would you be willing to share more more detail about your experience of caring for someone living with a mental health condition? If so, please type your first name and contact phone number or email address below.

Please note that any information you share will remain anonymous, and your details will not be used for any purpose other than to contact you for this research.

Name	
Email Address	
Phone Number	

Thank you for your time and very valuable contribution to help better understand the needs of carers of someone living with a mental health condition. We are very appreciative!

APPENDIX 2

Do you care for someone with a mental health condition?

Are you over 18 years and living in the Great South Coast Region of Victoria?

Do you have 15 minutes to have your say about improving carer support?

Yes? Then we need you!

We recognise that a carer's role is incredibly valuable, but can also be challenging. This survey has been designed to better understand your needs as a carer. The outcome of this project will be a resource (including clear recommendations) that will be presented to the Fight For Your Life working group to actively inform their work in supporting carers of people living with a mental health condition.

Complete our anonymous survey online
www.surveymonkey.com/r/HRL2DH9

For more information, or to request a hard copy survey, email
info@leadershipgreatsouthcoast.org.au

'Connecting with Carers
Great South Coast'
A LGSC Community Project

LEADERSHIP
Great South Coast

AUGUST 11 2017 - 5:45PM

Leadership Great South Coast team call for feedback from carers

Madeleine McNeil   Local News

With growing awareness of the challenges of those living with mental illness, the spotlight is now on their carers.

A new Leadership Great South Coast project aims to give voice to carers to change how they are acknowledged and supported.

Team lead Leon Carey said carers often felt invisible and unheard in community discussions about mental illness. "The lives of mental health carers, whether they're parents, partners, friends or family members, can change enormously," Mr Carey said.

Feedback wanted: Leadership Great South Coast members l-r Vicki Askew-Thornton, Leon Carey and Alison Kennedy want to hear from carers. Picture: Rob Gunstone

"Being a carer can be incredibly challenging and it can restrict people's lives in terms of their social activities, their career and even just their personal time and space. Often they are thrust into the role with no training or formal experience and very little support or recognition."

Mr Carey said the project team was gathering information and stories from carers with a view to create a new resource for mental health services.

This resource, which will be presented to the Fight for Your Life taskforce and Wellways Australia, will document carers' stories and provide evidence-based recommendations to organisations providing mental health support services.

The project will include an anonymous online survey and a series of interviews with carers who will be invited to share their experiences. To participate go to surveymonkey.com/r/HRL2DH9 or email info@leadershipgreatsouthcoast.org.au.

CONNECTING WITH MENTAL HEALTH CARERS IN THE GREAT SOUTH COAST